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ABSTRACT

A consultation was sponsored by the European Commission, the World Health Organization's Global Programme on AIDS, and the United Kingdom Department of Health to explore the specific needs of ethnic minority communities in European countries for culturally and linguistically appropriate Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) and sexual health services. It also aimed to develop a context for collaborative and integrated approaches to improving and enhancing such services. Thirty-five experts from government sectors, nongovernmental organizations, and ethnic minority organizations participated in a series of working groups addressing issues such as models of good practice of collaboration, provision of appropriate HIV/AIDS education for ethnic minority communities, and empowering ethnic minority communities to develop AIDS treatment, care, and support organizations for ethnic minorities. Participants developed recommendations based on good practice to guide European national AIDS programs in policy development. It was emphasized that it is important to realize that ethnic minorities do not form a homogenous group, and that diversity must be acknowledged. Representation of ethnic minority communities in decision making is essential to success in HIV prevention. Titles of 12 working papers prepared for the consultation are listed, as are consultation participants. (SLD)

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ED 405 445

Final Report

Shared Rights - Shared Responsibilities

European Consultation On Collaboration Between Government Sectors, Nongovernmental Organizations And Ethnic Minority Organizations In AIDS Prevention, Support And Care

5th-9th October 1995, London, United Kingdom

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COMMISSION OF THE EUROPEAN COMMUNITIES

WHO REGIONAL OFFICE FOR EUROPE
GLOBAL PROGRAMME ON AIDS

Meeting organised with financial support from the European Commission, World Health Organisation - Global Programme on AIDS and the UK Department of Health

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Title Final Report - Shared Rights, Shared Responsibilities

Publication This report is based upon the Standard Short Report of the meeting, written jointly by the Naz Project and the Global Programme on AIDS (WHO)

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Abstract ■ The consultation was organized to explore the specific needs of ethnic minority communities in European countries for culturally and linguistically appropriate HIV/AIDS and sexual health services. Further, it aimed to develop a context for collaborative and integrated approaches towards improving and enhancing such services. Experts from government sectors, nongovernmental organizations and ethnic minority organizations participated in a series of working groups addressing issues such as models of good practice of collaboration between the sectors, provision of appropriate HIV/AIDS education for ethnic minority communities, empowering ethnic minority communities to develop community-based AIDS service organizations and provision of appropriate treatment, care and support for people living with HIV/AIDS who belong to ethnic minority communities. Going through a process of identifying gaps and shortcomings in current service provisions and exchanging visions on ideal standards, participants developed a series of recommendations on good practice, appropriate education, empowering communities and appropriate care. The recommendations will guide European national AIDS programmes in developing policies in this area.

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Introduction

"Shared Rights - Shared Responsibilities: European Consultation On Collaboration Between Government Sectors, Nongovernmental Organizations And Ethnic Minority Organizations In AIDS Prevention, Support And Care", London, 5-9 October 1995, was organized by the Naz Project with support from the European Commission and the Department of Health, United Kingdom. The consultation was co-sponsored by the WHO Regional Office for Europe.

Mr Shivananda Khan and Mr Kim Mulji of the Naz Project formed the organizing team for the consultation, and Mr Khan welcomed the participants. Opening presentations were made by Ms V. Bahl, Ethnic Minority Advisor of the Department of Health, United Kingdom, Mr H. Mikkelsen, Global Programme On AIDS, WHO Regional Office for Europe, Ms A. Pollack, Member of the European Parliament and Dr J. Pillaye, Health Education Authority, United Kingdom.

35 participants from Denmark, Germany, Greece, Netherlands, Norway, Portugal, Spain, Switzerland, Belgium, France, United Kingdom attended the meeting. They were selected in the capacity of experts on issues related to HIV/AIDS, sexual health and ethnic minority communities from government sectors, nongovernmental organizations or ethnic minority organizations, with the view of having a fair representation of all sectors.

Recognizing the needs and rights of ethnic minority communities in European countries to HIV/AIDS and sexual health services, and the vulnerable position of these communities with regard to HIV infection and its adverse impact, the aim of the meeting was to bring the experts from different sectors together in a consultative process. During this process the specific needs of ethnic minority communities for culturally and linguistically appropriate services were explored and identified. Further, participants developed guidelines for national AIDS programme to ensure that the needs of the different ethnic minorities are addressed by national strategies for AIDS prevention, support and care and to create a context for collaborative and integrated approaches between government sectors, ethnic minority organizations and other nongovernmental organizations.

Good Practice

Collaboration ■

Governments are obliged to lead by example, demonstrating their commitment to provide accessible services to all people in their country. Ethnic minority communities have specific cultural, religious and linguistic needs with regard to HIV/AIDS education, prevention, treatment and care services. Accessibility can only be ensured, if these needs and the rights of ethnic minority communities to appropriate services are fully recognized by governmental and nongovernmental sectors. This recognition entails the creation of a coherent understanding of the specific needs of ethnic minority communities with regard to HIV/AIDS, dismantling cultural stereotypes and existing myths about HIV/AIDS. It is important to distinguish between the terms "culturally sensitive" and "culturally appropriate", the latter to be preferred. Attempting to adopt a culturally sensitive approach may lead to supporting denial by members of ethnic minority communities, e.g. with regard to the existence of extra-marital sex or men who have sex with men.

Appropriate services can best be developed through collaboration between governmental and nongovernmental sectors and ethnic minority communities based on equality, equity and partnership. The relations of governmental and nongovernmental sectors to ethnic minority communities are often impaired by lack of mechanisms for effective consultation with the communities. When such mechanisms do not exist, ethnic minority communities may experience services as being imposed upon them, rather than arising from the needs of the communities themselves. This experience is counterproductive, since it may increase denial and complacency.

Effective consultation includes appropriate representation of ethnic minority communities at all levels of decision making, but it is important to be aware of the pitfalls regarding representation. So-called community leaders may only be self-selected and acting as "gate-keepers" of the community. The issue of representation is complicated by the cultural dynamics around sexual behaviours and the concepts of honour and shame related to such behaviours. While these factors obviously have to be taken into account in the design and planning of services, they also affect the response of individuals and communities and may lead to denial or complacency within organizations representing ethnic minority communities.

To develop adequate, appropriate and equitable service delivery, issues of equity and equality within services need to be identified and addressed through policies and appropriate training at all levels of governmental and nongovernmental agencies. The principles of equity and equality must be reflected in the composition of decision making bodies and management and in policy making regarding staffing and volunteering. The impact of cultural stereotypes on current service provision and strategic planning must be carefully assessed and addressed.

Many agencies believe that the most appropriate approach for HIV/AIDS service delivery is an "integrationist' or "colour-religious-cultural blind" framework. This belief is centred on the concept of equal access for everyone. The appropriateness and accessibility of services are, however, determined by issues of language, terminology, literacy, cultural dynamics, racism etc. Integrationist approaches tend to ignore the specific needs of ethnic minority communities as well as the impact of racism on service delivery and may not be the most appropriate framework for service delivery to marginalized communities.

Participation in fora for exchange of information are important for members of community-based organizations (CBOs) because CBOs in other localities may be addressing similar issues and may well have developed appropriate strategies. Through such forums it may be possible to exchange such knowledge and avoid "reinventing the wheel". Mechanisms should be established to support such fora and to disseminate information among CBOs.

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Funding

Though CBOs play a vital role in the provision of appropriate services, there are a number of barriers hampering access to funding for CBOs, including language barriers, funding procedures, difficulties in completing forms and lack of training and experience in designing programmes and services. Funding procedures are usually dictated by funders and seldom geared to the needs of ethnic minority CBOs. This means that funding is restricted to the few CBOs, who understand and comply to the values and bureaucratical standards of the host culture. Funding is often provided only in the form of short-term project support. This type of support neither takes into account the need for community development processes, nor the need to cover core costs such as salaries, management and revenue costs. Often funding provisions require specific methods of monitoring and evaluation. Services developed to cater for the needs of ethnic minority communities may well need to have different operating structures, different methodologies of delivery and different frameworks of access not compatible with such methods of monitoring and evaluation.

Further, funding resources are often allocated in accordance with the level of known HIV prevalence and the number of those living with AIDS. Consequently, communities with low level of HIV testing may be considered less of a priority. Community dynamics have an impact upon the way illness is perceived, and can therefore have an effect upon the reporting of illness. Many members of ethnic minority communities access other networks of diagnostic support, such as Hakims and Auryvedic practitioners. Funding should not only reflect the need for care and support reflected by the caseload, but equally the prevention potentials. Funding priorities should also be based on an assessment of risk situations and risk potentials within ethnic minority communities.

Improving the efficiency of prevention and care services, the implementation of policies of equality and equity within governmental and nongovernmental organizations is likely to result in long term savings of human and financial resources. Still, such policies have immediate cost implications which have to be acknowledged and accounted for.

APPROPRIATE EDUCATION

Research

There is only little research and needs assessment done with regard to the specific issues of HIV transmission within ethnic minority communities, including social behavioural research on risk situations and risk behaviour. Where research has been done, methodologies tend to ignore the cultural dynamics and context and other issues of relevance to research into ethnic minority communities. Such issues must be considered at all levels and stages of the research, including the objectives and design of studies, the framing and terminology of questions, the selection of interview persons, the training of researchers on cultural issues, the collection, analysis and presentation of data, safeguards for the publication of sensitive information and the application of research results in prevention and care strategies.

These considerations are particularly relevant to research on sexual behaviours in ethnic minority communities. Such research tend to be framed by models of sexual behaviours and identities defined by terms such as "gay", "homosexual", "heterosexual", "bisexual". Such terms and identities are inappropriate to the cultural dynamics of many ethnic minority communities.

In addition to social behavioural research, there is a need for research on the social, economic and health factors affecting ethnic minority communities and on the impact of such factors on HIV/AIDS transmission and its consequences within the communities.

Education and prevention

The terms of education and prevention are often confused. In this context it may be useful to define education as the process of raising awareness in communities about HIV/AIDS by providing accurate information. Prevention can then be defined as the processes enabling individuals in the community to modify risky behaviours towards safer practices and maintaining such behaviour changes. In this way education and prevention require different resources and different approaches.

Whether the developing agency is a governmental or nongovernmental organization, or an ethnic minority CBO may strongly influence the quality as well as the acceptance and impact of the material. If CBOs are properly resourced, they are in the best position for this task. Resources should be provided for all steps of the development of materials, including funding for the production of appropriate imagery and text, and pre-testing of materials. Skills of CBOs staff can be enhanced through training on resource material development. The process of developing materials can at the same time be a process of increasing awareness and knowledge within the community.

It is important to ensure that resource materials are culturally and linguistically appropriate in terms of imagery and text. This consideration should not be confused with the notion of being sensitive. Too often misplaced sensitivity, the fear of outside people of offending communities, determines the content of imagery and words in a way that render the information useless or leave out important messages. Differences within communities must be acknowledged just as much as differences between communities. Resource materials should be targeted to specific behavioural groups such as drug users, men who have sex with men, male and female sexworkers, young people and women.

Further, when materials are mere translations of materials made in the language of the host country, they ignore the cultural context and may end up giving messages which are misinterpreted or not understood. European terminologies around sexual identities and sexual behaviours may not be appropriate within community languages and communities. Whenever possible, materials should be prepared in the community language, and if necessary, checked contentwise by translating them into the language of the host country. When it is only possible to prepare materials translated from another language, it is important to ensure that translators are trained around HIV/AIDS, sexual identities, sexual behaviours, gender and sexual health.

When preparing materials, the following factors are important to consider: the level of literacy with regard to the language of the host country as well the community language, the level of sex education and sexual knowledge of people from ethnic minority communities, respectively women, men and young people, the power dynamics that reflect gender, class, age, caste, disability, education within these communities and families, the differing frameworks of gender constructions, male and female roles, the relationships between children and parents and extended family relatives within ethnic minority communities.

Education and prevention resource materials should always be pre-tested for effectiveness, before they are finally published and widely distributed. The pre-testing procedure should not be done randomly, but ensure that that the messages are appropriate and relevant to the target groups.

Finally, appropriate channels for communication and distribution of materials within the ethnic minority communities should be identified.

Many European countries have similar ethnic minority communities. Local CBOs as well as already existing networks such as the European Ethnic Minority Network and "AIDS and Mobility" may be strengthened through the establishment of an electronic network via the Internet to facilitate collaboration and information exchange about the appropriate provision of resources and training.

EMPOWERING COMMUNITIES

Community development

The vulnerability of ethnic minority communities to HIV infection and its adverse impact is determined by a range of societal factors and structural conditions, including employment opportunities, educational opportunities, housing, access to health care or social care, mental health policies and treatment, the justice system and so on.

Religious and cultural issues are equally important factors, since they are closely linked to issues around sexual and drug using risk behaviours. Within some ethnic minority communities, especially Muslim identified, the relationship between the religion of the communities and the predominant religion of the host country, Christianity, has become an important point for debate and scrutiny. This discussion also touches upon the relationship between culture and religion and has implications for the experience of individual identity as well as of community/cultural identity. In the context of HIV/AIDS, denial of risk behaviours may become a part of community identity and strength as a way to safeguard community honour and sanctity. Obviously public denial of risk behaviours does not necessarily mean that the behaviour does not exist. It is, however, imperative that these dynamics are understood and recognized as a major factor in developing appropriate services and programmes.

To address the social factors mentioned above, and to overcome denial within the ethnic minority communities, HIV/AIDS should be addressed within the framework of sexual health and community health as a part of a broader strategy for community development. It is vital that HIV/AIDS services are not experienced as being imposed upon the communities which may increase denial, but are seen as arising from the needs of the communities.

Governmental and nongovernmental organizations often lack awareness and knowledge of the psycho-social dynamics of ethnic minority communities, or how behaviours and identities are contextualised within these culture specific dynamics. Therefore, as a first stage of a community development approach, members of ethnic minority communities and ethnic minority CBOs should be encouraged to develop their own community based services to HIV/AIDS, e.g. through financial support, training in organizational development, structuring programmes, prevention frameworks and funding processes etc. Further, ethnic minority CBOs should be actively supported to conduct relevant research and needs assessments.

In addition, governmental and nongovernmental agencies should recruit more ethnic minority staff at all levels in their organizations. Further more, competent ethnic minority CBOs should also be facilitated to provide training and consultancy on the issues and needs of ethnic minority communities, and the delivery of culturally and religiously appropriate services to the broad range of service providers. Such training may also be included in the education and training of medical doctors, psycho-therapists, psychologists, psychiatrists, police and staff of education, health and social services.

Finally, ethnic minority representatives should be seen as working partners in all policy making forums by governmental and nongovernmental agencies. Where necessary appropriate training should be given so that they are empowered to actively participate in national, regional and local debates around HIV/AIDS.

Human rights of ethnic minority communities

Human rights must be respected for all people regardless of their national origin, race, colour, creed, gender, sexuality or HIV status and legal instruments should be used or implemented to ensure these rights are upheld. As a major step in empowering and developing ethnic minority communities, racism must be tackled by governmental and nongovernmental agencies to reduce the marginalization and disempowerment of individuals and communities. Racism is not only about a person's colour. It has implications with regard to religious and cultural differences and can be both overt and covert, individual as well as institutional.

Effective monitoring of services should be introduced to combat discrimination based on ethnic background. Racism at all levels needed to be challenged affirmatively and

proactively as it affects the ability to deliver services and the access to those services. Equal opportunities policies in terms of employment and delivering services must be implemented to ensure full and equal access to services, and to avoid discrimination.

Defining ethnic minority communities in terms of "migrants", "guest workers", "foreigners" can enhance the disempowerment of communities, adding to the sense of marginalization and stigmatization. Further, it can be very misleading, as persons perceived as "migrants" and "guest workers" often are born in the country and have families who have lived in that country for several generations.

APPROPRIATE CARE

Specific needs of ethnic minority communities

There are a range of issues related to the specific impact of HIV infection on persons belonging to ethnic minority communities.

Firstly, the framework for pre-test and post-test counselling may have special implications for persons belonging to ethnic minority communities who have languages, world-views, religion etc. differing from the counsellor. To ensure informed consent with regard to testing and treatment, services which include interpreters or community language counsellors should be made available for members of ethnic minority communities. The complexity and profound significance of confidentiality in small close communities with specific socio-cultural dynamics of honour and shame must be understood in governmental and nongovernmental provided services.

There appears to be a lack of knowledge about the health impact of HIV/AIDS on persons belonging to ethnic minority communities. There is little knowledge about the opportunistic infections that are predominantly acquired by people from ethnic minority communities and more prevalent in their communities, and about the length of time between infection and illness with regard to people from ethnic minority communities. Guidelines on appropriate nutrition and diet for persons belonging to ethnic minority communities are yet to be developed. Drug treatments have not yet been tested to find out if they have different impact on persons belonging to ethnic minority communities.

People from ethnic minority communities find themselves particularly isolated when they are living with HIV or AIDS. Dynamics of honour and shame may lead to their individual marginalization within communities, and their ethnicity acts as a framework of marginalization and stigmatisation in the outside world. Many members of ethnic minority communities have relatives and friends still living in their countries of origin. If a person is affected by HIV/AIDS, one of the possible service frameworks is to have friends and relatives providing support. However issues around immigration, visa restrictions and related factors, often mean that family members and friends are not able to visit the country. This can isolate a person even further.

Living conditions below average with regard to housing, child care, financial support and recreation tend to reduce the quality of life for people from ethnic minority communities with HIV/AIDS and their families

Many cultures have different understandings of death and dying, different ways of grieving and different religious and social practices around illness and death. The preparation for death and the funeral must respect and reflect such understandings and practices to be culturally sensitive and appropriate, and should include repatriation of the body when appropriate, with confidentiality, after death.

Access to services

Most HIV/AIDS care and support services for ethnic minorities are currently provided within the context of the host country's cultural dynamics and perceptions, and therefore often inappropriate or inaccessible to members of ethnic minority communities due to language barriers, their location, the design of services etc.

Racism, as well as religious and cultural ignorance of staff of governmental and nongovernmental service agencies and of other service users, represents a major barrier for people from ethnic minority communities to feel accepted. The perception of the medical and psychiatric professions about ethnic minority communities and their cultural dynamics needs to be explored.

Support groups of people living with HIV/AIDS are often based on the belief that the mutuality of living with HIV/AIDS creates the mutual support and solidarity needed. Experience of overt and covert racism within such groups precludes participation and thus denies such support.

The actual location and physical environment of services can also have a major impact in terms of service take-up of different agencies. The visibility and identity of the service

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agency, perceptions of environment, front-line staff attitudes and language, posters displayed etc. create a discrete environment, which may be inappropriate for people from ethnic minority communities.

There is a lack of acknowledgement by service providers to cultural specificity in terms of sexual identity/behaviour, personal and family customs, family structures, networks, and inter-family relationships which prevent access to services. Further many members of ethnic minority communities feel unable to utilise mainstream services, because of their immigration status, distrust of the medical profession, fear of the police etc. Access to trials and treatment of people living with AIDS from ethnic minority communities is hampered by lack of information about trials and treatment in community languages.

Care givers to people living with HIV/AIDS from ethnic minority communities are often unsupported and working alone. Support should be given in the form of additional specially trained and culturally appropriate workers who can provide continuous practical help. Further culturally appropriate psycho-social support should be made available to care givers on a long-term basis.

A culturally and religiously appropriate diet is of great importance while a person is hospitalized or ill in bed at home. Access to culturally and religiously appropriate pastoral care should be made available through community networks and agencies.

Conclusions of Consultation

Participants stressed that in the context of HIV/AIDS and ethnic minorities it is important to realize that ethnic minorities do not form a homogenous group. On the contrary there are many different ethnic minority communities living in the European region, and differences within each of the communities. An important guiding principle is therefore the recognition of diversity at local, regional as well as national level. Further, it must be acknowledged that ethnic minority communities do not form a separate entity distinct from other vulnerable groups such as people who inject drugs, sex workers and clients, men who have sex with men etc. There are links between the groups, in the sense that each of the other groups are represented also within ethnic minority communities.

Further, it should be realized that ethnic minority communities are at a different stage of organizational development throughout Europe. This implies that a uniform structures for ethnic minority community-based organizations cannot be prescribed either at a local, national or European level.

Representation of ethnic minority communities in decision making bodies at all levels is essential to success in the field of HIV prevention, support and care for ethnic minority communities. The guiding principle of such representation should be inclusion of as many different communities and groups within those communities as possible. Community leadership should not be considered the only criteria for representation, equally or even more important is commitment and understanding of the dynamics of HIV transmission within the communities.

Efforts in education, prevention and care should be guided by the essential principle of holism. Regarding ethnic minority communities this implies that such efforts can only take place within and acknowledging the context of culture, religious belief and language. A holistic approach to care includes medical as well as psycho-social aspects, and availability of care throughout the course of the HIV infection - from diagnoses of the infection to the last stages of the illness.

Members of ethnic minority communities are not isolated from their countries of origin. Many travel frequently to these countries for a variety of reasons. Bi- or multilateral collaboration should be developed to provide information about the risk factors of HIV transmission within these countries, legal structures, and access to HIV/AIDS services.

Recommendations from Consultation

National AIDS committees should ensure that the specific cultural, religious and linguistic needs of ethnic minority communities with regard to HIV/AIDS are adequately met through an equitable partnership between governmental, nongovernmental and ethnic minority CBOs, including:
involvement of ethnic minorities CBOs in needs assessments and all other stages of planning, delivery and evaluation of services
training programmes for members of ethnic minority communities towards empowering such communities to develop a community-based response to HIV/AIDS. e.g. on book-keeping, management, facilitation skills, report writing, funding applications, project proposals, and resource material development enabling ethnic minority CBOs to provide training and consultancy on culturally and religiously appropriate approaches to the broad range of service providers, for example in the training of medical doctors, psycho-therapists, psychologists, psychiatrists, police, education, health and social service staff supporting the establishment of local, national and regional fora for ethnic minority CBOs and enabling ethnic minority CBOs to actively participate in local, national and regional fora and meetings of governmental and other nongovernmental organizations

National AIDS committees should ensure that all service providers have clearly defined equal opportunities policies and integrated culturally appropriate services for ethnic minority communities through:

- recruitment of ethnic minority staff at all levels in governmental and nongovernmental organizations; provision of training on culturally appropriate service delivery for staff and volunteers within these organizations
- introduction of effective monitoring of all services to combat racism and discrimination based on ethnic and cultural background

National AIDS committees should take action to ensure that governmental organizations lead by example and demonstrate their commitment to providing accessible and appropriate services to ethnic minority communities.

National AIDS committees should ensure the provision of adequate and continuous financial support to the development of culturally and linguistically appropriate HIV/AIDS prevention, support and care services for ethnic minority communities by:

- adjusting funding procedures and policies to the needs of ethnic minority CBOs, e.g. simplifying funding procedures, forms and routines and mechanisms of monitoring and evaluation
- allowing realistic time-scales in project funding and development
- allowing inclusion of core costs (salaries, management and revenue costs etc.)
- providing assistance and training in project/programme design, management and funding procedures
- allocating resources to ensure appropriate training for members of ethnic minority communities on creation of community based responses to HIV/AIDS

Institutions of the European Union and national governments should ensure that members of ethnic minority communities in the Europe Union have access to appropriate services wherever they move, support the establishment of a European electronic network of ethnic minority CBOs via the Internet to facilitate collaboration and information exchange throughout one country and/or the European Union.

In order to develop appropriate services, national AIDS committees should encourage, facilitate and support research, in particular by ethnic minority CBOs, on social, economic and health issues affecting ethnic minority communities, including:

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- sexual identities, behaviours and terminologies within a historical and cultural contextualisation
- condom and contraceptive use
- drug use, including injecting and other drug using behaviour
- HIV and AIDS prevalence within different ethnic minority communities, e.g. through sentinel HIV surveillance based on unlinked anonymous testing
- treatment options which are appropriate to the needs of people from ethnic minority communities
- issues affecting in particular women, young people, men who have sex with men, and women who have sex with women

Recognizing the range of ethnic minority communities and groups within these communities, national AIDS committees should support the development of a diversity of culturally and linguistically appropriate approaches to HIV/AIDS education and prevention, including:

- educational and prevention resource materials written in the appropriate language of the target community
- training on HIV/AIDS, sexual identities, behaviours and terminologies, gender and sexual health for translators of resource materials
- use of culturally and religiously appropriate imagery
- use of other culturally appropriate education approaches, e.g. dance, theatre, literature and film, pre-testing of education and prevention resource materials for ethnic minority communities utilizing ethnic minority CBOs.

National AIDS programmes should identify gaps in care services for ethnic minority communities through needs assessments, preferably conducted by CBOs, in consultation with ethnic minority communities and those marginalized within them, such as men who have sex with men, sex workers, drug users etc.

National AIDS committees should ensure that people from ethnic minority communities receive culturally and linguistically appropriate pre-test and post-test counselling by:

- using, where possible, appropriately trained staff from ethnic minority communities
- training of staff at testing sites on relevant cultural and religious issues
- training translators, advocates and community language counsellors

National AIDS committees should address the double discrimination faced by people from ethnic minority communities living with HIV/AIDS through the following means:

- use of local ethnic minority media to address the issues people living with HIV/AIDS
- support efforts of ethnic minority CBOs to combat denial in ethnic minority communities
- enabling ethnic minority CBOs to document human rights abuses and ensure that such abuses are addressed.

- ensuring the inclusion of people from ethnic minority communities in drug treatment trials, e.g. by making information of such trials available in various languages,
- ensuring that the preparation for death and the funeral can be made in accordance with different cultural understandings of death and dying and include where appropriate repatriation of the body.

Recognizing the specific needs of care givers from ethnic minority communities, national AIDS committees should ensure

- support to care givers in terms of trained workers who can provide continuous practical help
- provision of culturally appropriate psycho-social support to care givers on a long term basis.

WORKING PAPERS

1 ■ Report of the Second European Meeting for the Exchange of Information on: Ethnic Minorities, Migrants and AIDS - Focus on Human Rights and AIDS. Alden Biessen, Belgium, 2-5 June, 1994.

2 ■ Socio-Economic Situation of the Black Community. Papers presented by Dr. Jayshree Pillaye, of the Health Education Agency, UK, presented at a seminar of Refugee Community Organizations Racism, AIDS & HIV Prevention.

3 ■ Issues to Consider in Meeting Patient's Charter Standard One. Religious and Cultural Beliefs, paper presented at a seminar on Death and Dying, UK, 1995.

4 ■ Religion and Sex Education. Abstract from a Sex Education Forum, UK report on religions and ethnic minorities. Published 1994

5 ■ HIV/AIDS and the Needs of Refugees in Perspective. Omwony Ojwok, Merton and Sutton District Health Authority, UK, 1993

6 ■ Eurocentricity in Health Promotion - paper presented by Bradford Action on Health, UK, 1994.

7 ■ A Community Commitment - paper presented by Shivananda Khan at the Naz HIV/AIDS Pan-European Conference for South Asians and Muslims, UK, September 1992.

8 ■ Ethnic Minorities and Migrant Communities in Europe: Race, Culture and Sexuality. Paper by Shivananda Khan, presented at the Social Aspects of AIDS conference, Berlin, 1994.

9 ■ Race, Culture and Sexuality. Extracts from Naz Report, 1994.

10 ■ Empowerment of marginalised communities to develop their own HIV/AIDS service organizations to provide education, prevention and support services. Paper presented by Dr. Dima Abdulrahim to the IXth International Congress on AIDS, Berlin, 1993.

11 ■ Summary of report on First Information Exchange Meeting on Ethnic Minorities, Migrants and AIDS. Blossen, Germany, 1993.

12 ■ Recommendations drawn from the Conference Report of then Naz European Conference on HIV/AIDS for the Muslim and South Asian communities. London, UK, 1992.

Note ■ Please contact the Naz Project for information on accessing any of these papers.

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